

The logo for MS Society, featuring the text "MS Society" in white on an orange triangular background pointing to the right.

**MS** Society

A close-up portrait of a young woman with blonde hair in a braid, wearing red-rimmed glasses and a red top. She is smiling slightly and looking directly at the camera. The background is a warm, orange-toned wall.

**Just diagnosed**

We're the MS Society. Our community is here for you through the highs, lows and everything in between. We understand what life's like with MS.

Together, we are strong enough to stop MS.

We rely on the generosity of people like you to fund our vital work. If you would like to make a donation, you can do so by:

- Calling us on: **0300 500 8084**.  
Lines are open Monday to Friday, 9am – 5pm
- Visiting us at: **[mssociety.org.uk/donate](https://mssociety.org.uk/donate)**
- Posting your donation to: MS Society, National Centre, 372 Edgware Road, London NW2 6ND. Please make cheques payable to the 'MS Society.'

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# A word from Cath, who has MS

It took about four years for me to be diagnosed. Right up to the final test, I was being reassured by the doctors that my symptoms were due to a spinal cord injury in my neck.

So when the diagnosis was confirmed, I was in a state of shock. I didn't want to tell my family, especially my daughter.

I don't know where I'd have been without the online forums. They've become like friendship groups.

People there understand the condition better than medics because they have first-hand experience of it. They can give tips that doctors aren't taught, especially with some of the unusual symptoms.

But it's not all doom and gloom. You also talk about hobbies and other things. You don't feel alone anymore and it's all very supportive.

I now know that there are lots of different treatments for symptoms. And if one doesn't work or has side effects, there are usually other options. There are lots of health professionals who can help, such as your MS nurse, continence nurses, physiotherapists, dietitians and your GP.

Oddly, I feel less stressed now. I'd always had high expectations of myself in my career and was a stickler for a clean, tidy home. Now if I've made someone smile today, I feel that I've achieved something. What I can't do today I do tomorrow. I look at things in a totally different way now.

A handwritten signature in black ink that reads "Cath". The letters are cursive and slightly slanted to the right.

# Five things to know

- 1** Most people are diagnosed with relapsing remitting MS. The other 10-15% are diagnosed with primary progressive MS
- 2** A combination of our genes, things in our environment and our lifestyle could all play a part in why people get MS
- 3** The last twenty years have seen huge advances in how relapsing MS is treated. Recently we've seen more exciting breakthroughs, especially for people whose MS is relapsing
- 4** If you've been diagnosed with relapsing MS, doctors recommend that you start taking a disease modifying therapy (DMT) as soon as possible after you're diagnosed
- 5** Life with MS these days is more about what you can do, not what you can't. We're here to support you, with information, the MS Helpline, grants, our local groups and our online forum



# About this booklet

This booklet is for you if you're going through a diagnosis of MS, or have already been diagnosed with it. It'll also answer many of your questions if you're the partner, relative or friend of someone with MS.

Whatever your situation, you may be going through a huge range of emotions. Among them can be anger, shock or fear. You might even feel relief if it's taken some time to be diagnosed.

This booklet gives you an introduction to MS and points you towards other information and support if you need it. Your neurologist and, if you have one, your MS nurse are also there to answer your questions.

Find out more about MS and what support is available at **mssociety.org.uk** You can ask questions and get support on our online forum. There you'll find other people who

know what you're going through. It's at **mssociety.org.uk/forum**

If there's something on your mind, you can call the MS Helpline on **0808 800 8000** (closed weekends and bank holidays). Or email them on **helpline@mssociety.org.uk**

You can also send them a private message by visiting our Facebook page **facebook.com/MSSociety**. Use the 'send message' tab under the main picture.

The MS Helpline will also have details of our online support for recently newly diagnosed people and for their friends and family.

One last thing. Where you see a word in bold in this booklet, it means you can turn to the back and find it explained.

# What is MS?

Multiple sclerosis (MS) affects the nerves in your brain and spinal cord.

Together these two things are known as your central nervous system (CNS).

You can't catch MS from someone. You get it when your **immune system** isn't working properly. In MS your immune system attacks your **nerves** by mistake.

These nerves control lots of different parts of your body and how they work. That's why, if you have MS, you can get its symptoms in many parts of your

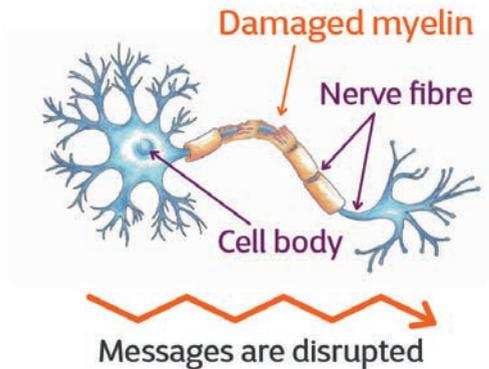
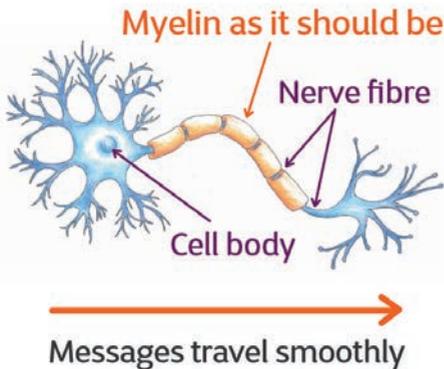
body, and it can affect lots of things your body does. This is why everyone's MS is different.

## What's happening in MS?

Your immune system protects you from infections. It does this by attacking and killing viruses and bacteria that get into your body.

But in MS your immune system attacks nerves in your brain and spinal cord by mistake. This damages the covering around your nerves.

This covering is made of a fatty coating called **myelin**. It protects



each nerve from harm and helps messages travel along it.

When myelin becomes damaged, messages find it harder to pass along the nerve – or messages can't get through at all. That's when symptoms of MS begin. Eventually so much damage takes place that it can't be repaired, and the nerve dies.

Damage to nerves can cause MS symptoms that are easy to see, such as difficulties walking, or problems with your balance. But many symptoms can't be seen by other people, such as **fatigue**, pain or unusual feelings in your skin, or bladder and bowel problems.

## Types of MS

Everyone's MS is different, but most people will be diagnosed with one of these main types:

- relapsing remitting MS
- primary progressive MS
- secondary progressive MS

We explain these over the next two pages. Knowing what type of MS you have won't tell you how your MS will develop over the years to come.

MS is unpredictable. No two people are affected in the same way. For some there'll be growing difficulties and disability. For others life goes on without major problems.

## Relapsing remitting MS

This is the type most people with MS – around 85% – are first diagnosed with. It's often just called 'relapsing MS'.

When you have this type, you have relapses (attacks of symptoms). These can last days, weeks or possibly months, then mostly or completely get better.

In the early stages of relapsing MS, your symptoms often get better between relapses. This is known as 'remission'. But symptoms might not completely go away. That depends on how much damage has been done to the myelin or to the nerve itself.

In online forums and elsewhere you often see this type of MS shortened to 'RRMS'.

Read more about this type of MS in our booklet 'Understanding relapsing remitting MS'.

## Primary progressive MS

If you have primary progressive MS, you get a steady build-up (or ‘progression’) of symptoms over time with no periods of remission. You usually don’t have relapses.

Primary progressive MS is less common than relapsing MS. About 10 to 15% of people who are diagnosed with MS are told they have this type.

You might see this type of MS shortened to ‘PPMS’.

Some people (about 1 in 20 of all people with MS) who have primary progressive MS from the start also have relapses on top of a gradual worsening of their MS.

This is called progressive relapsing MS. This label is gradually being replaced by the term ‘active progressive MS’.

You might see this type of MS shortened to ‘PRMS’.

## Secondary progressive MS

Many people with relapsing MS will, years later, see it turn into secondary progressive MS.

In the past this has happened, on average, to around two out of three people within 15 years of them being diagnosed with relapsing MS.

It can be hard to tell when you move to this type of MS. But it’s usually diagnosed once your disability has got worse over at least six months and you’ve stopped having relapses (or they happen much less often).

No one’s MS starts out as secondary progressive. But a few people are told they have this type when they’re first diagnosed if they’ve had unexplained symptoms for a long time.

You might see this type of MS shortened to ‘SPMS’.

You can read more about this type of MS in our booklet ‘Understanding progressive MS’.

**“MS doesn’t have to mean a life sentence. Yes, it’s serious and yes, it does change your life... but you can still enjoy your life.”**

**Louisa**



# First questions

## Why do people get MS?

We don't know what the exact cause of MS is. We do know that there's not just one single reason.

There are probably a number of things involved: your genes, your environment and your lifestyle.

Some of these you have no control over. But people can do something about smoking, weight and vitamin D levels to lower their risk of getting MS if it's in their family.

## Your genes

MS isn't directly inherited like some conditions. It's likely that a combination of things cause MS – and genes are one of these.

The child of someone with MS has a higher (but still low) chance of getting it themselves, compared to the child of someone who doesn't have MS.

MS isn't directly passed on from a parent to their child. There's no

### Risk of MS in your lifetime

There's about a 0.3% chance that someone will get MS in their lifetime. That means around 1 in 330 people will get it.

#### But if you have:

#### Your risk of getting MS is:

a <b>parent</b> with MS	about a <b>1.5%</b> chance (around <b>1 in 67</b> of these children get it)
a <b>brother or sister</b> with MS	about a <b>2.7%</b> chance (around <b>1 in 37</b> of these brothers and sisters get it)
a <b>child</b> with MS	about a <b>2.1%</b> chance (around <b>1 in 48</b> of these parents get it)
an <b>identical twin</b> with MS	about a <b>18%</b> chance (around <b>1 in 5</b> of these twins get it)

Your risk is around **1%** if an aunt, uncle, cousin, nephew or niece has MS.

one gene that causes MS. In fact, over 200 genes might affect your chances of getting it.

Genes alone don't decide who gets MS. Identical twins have the same genes. But when one gets MS, the other usually doesn't get it. That twin does have a higher risk of getting MS but most don't get it. This shows genes play a part but it's far from the whole story.

## Your environment

We know that you're more likely to get MS if you live further away from tropical countries near the equator. There are fewer people with MS in these sunny countries.

There are many more in countries further from the equator. This includes places like the UK, Scandinavia, Canada and the northern USA, southern Australia and New Zealand.

This tells us there's something in the environment that could play a role in MS.

More and more evidence shows that if you have low levels of vitamin D, especially before

you become an adult, this may increase your chances of getting MS. Vitamin D is known as the sunshine vitamin. Our bodies produce it when sunlight shines on our skin.

Research has also looked into whether an infection, such as the Epstein Barr virus, can trigger MS. This virus can cause glandular fever in teenagers and adults.

Most adults have had this this infection, so getting it doesn't mean you'll get MS too. But if you've had this virus, the chance of that happening is higher.

Other infections might also have a role to play, but it's not clear exactly what.

## Your lifestyle

### Smoking

Studies show you're more likely to get MS if you smoke. And if you have relapsing MS and smoke, your MS is more likely to get worse faster. For example, you're more likely to get more **lesions**, disability and **relapses**. Your MS is also more likely to change into

secondary progressive MS years sooner if you smoke.

We don't know yet for certain why smoking has these effects. Passive smoking – breathing in other people's smoke – might also be linked to getting MS but more studies are needed to be sure.

Smoking makes some MS drugs work less well. People on these drugs and who smoke get more relapses than non-smokers get.

If you have relapsing MS, studies show that stopping smoking could slow down how fast your MS changes to secondary progressive MS.

So it's a good idea to stop smoking if you already do. Then these risks quite quickly go down to those of a non-smoker.

### Diet and nutrition

Research shows if you're **obese** (very overweight) before your 20s, you're more likely to develop MS.

This is also true for people who don't have enough Vitamin D in their bodies.

We know now that it's important to stick to a balanced diet like the one recommended by NHS Choices – and to get more vitamin D if your body doesn't have enough of it.

If you have MS, or you're related to someone with it, an MS specialist can advise you about taking vitamin D supplements. If you decide to take them, you'll need more than official guidelines recommend for the general population.

Your GP can help you to stop smoking, and give advice on vitamin D and healthy eating. They can refer you to specialist support.

### MS is no one's fault

Hearing about things that may cause MS might make you ask: 'Could I have done something to avoid it?'

But you couldn't, because we don't know for sure which things come together to cause MS in each person. Besides, in the past we all knew much less about what might cause MS. You weren't likely to be in a position to do anything to lower your risk.

## What's going to happen now?

The short answer is that nobody knows.

MS is unpredictable and no two people are affected by MS in the same way. There's no standard pattern that your MS will follow. Even knowing what type of MS you have won't tell you how it will develop.

It's impossible to know how quickly your MS will get worse, or what parts of you will be affected. Symptoms can occur randomly, at any time, in any order. And if you get relapses, you won't know when your next one will be.

Being tired, stressed, ill or feeling too hot can make your symptoms worse. Getting an infection can trigger a relapse.

Your symptoms can change from day to day, or hour to hour, and for no obvious reason. You may also find you have days, weeks, months and sometimes years when you feel fine, with no obvious or difficult symptoms.

This unpredictability, and not knowing what the future holds,

can be one of the hardest parts of living with MS. It can take some time to come to terms with it, but there's support available.

You can talk things through with your MS nurse, if you have one. Or talk to someone on the MS Helpline on **0808 800 8000** (closed at weekends and on bank holidays).

Through our local groups you can get in touch with experienced volunteers. And our online forum is there to share what you're going through and answer questions. It's at [mssociety.org.uk/forum](https://mssociety.org.uk/forum)

You can read more about the emotional effects of MS in our booklet 'MS and your emotions'.

## Am I going to die from MS?

People don't die directly from MS. But someone with advanced MS who has many complicated symptoms can be more likely to pick up infections. These can be very serious, even life-threatening.

At the moment people with MS live on average about seven years less than people who don't have it.

But this gap could be closing as treatments get better.

## Can MS be cured?

At the moment, there's no cure for MS. Once you've been diagnosed with MS, you have it for life.

Research is trying to find ways to stop MS. Until then, there are ways to manage your condition.

This includes disease modifying therapies (DMTs).

If you have relapsing MS, a DMT can curb how many relapses you have or how bad they are. And it can also slow down how fast you're likely to become disabled.

The dozen or so DMTs we have work for relapsing MS. The first drug that can help with early primary progressive MS came along in 2018.

Read more about treatments on pages 22 and 23.

## Will I need to use a wheelchair?

This is a question a lot of people with MS ask when they're first

diagnosed. Because we don't know how your MS will affect you, it's impossible to answer.

Some people with MS will need to use a wheelchair at some point, either all or some of the time. Symptoms, such as **fatigue**, weakness, balance problems or when your muscles contract and feel stiff and tight (spasticity), can make walking safely difficult or impossible. But most people with MS will never need to use a wheelchair.

People who do need one find it lets them do things they wouldn't be able to do otherwise. They can carry on with their everyday activities.

## Can I still have children?

Yes. Having MS doesn't mean you can't get pregnant or father a child. So it shouldn't stop you from having children.

If you're a woman, having a baby won't affect your MS. There's no evidence that pregnancies make MS worse. In fact studies show it might mean you get less disability in the long run.

This might be because hormones in pregnancy make MS less active.

That said, if you don't take a DMT, relapses are more common within a few months after giving birth.

If you're on a DMT, it's important to get specialist advice from your neurologist or MS nurse before getting pregnant or deciding to stop treatment.

If you're a woman of childbearing age, talk to your neurologist about using reliable contraception (the 'pill' or condoms) while on these drugs. This is true while you're on the drug and for up to three months after you stop taking it.

Some DMTs might harm unborn babies. Others seem far less risky for pregnant women to use. One DMT, Copaxone, has a licence that says pregnant women can take it.

Men and women with MS who want to have a child should talk this over with their neurologist. If you're a woman and you think you may be pregnant, let your neurologist know straight away.

See our booklet 'Disease modifying therapies (DMTs) for

MS' and our individual DMT factsheets for more detail about each drug and how it might affect a pregnancy.

### **Will my children get MS too?**

Many people with MS worry that their children will get it as well. There's a small chance that this will happen, but there's a much bigger chance that it won't.

If you have a close relative with MS, the chances you'll get it are a bit higher, but the risk is still low. The figures from the latest studies are on page 12.

If you have MS and you want a child, there's only about a 1 in 67 chance he or she will get it too.

### **Will I have to give up work?**

Being told you have MS can make the future seem uncertain. It's natural to worry about the effects on your job, home and money. Over time you're likely to reassess things and adjust, but it's important not to rush into any major decisions.

Because MS is unpredictable and people do all kinds of different

jobs, it can make the workplace situation difficult. Some people do find that work – or the kind of work they've been doing – is no longer possible. But many people carry on working.

To do this you may find that you need to make changes. These could be to your workplace, the work you do or how you do it.

These changes are known as 'reasonable adjustments'. The Equality Act and, in Northern Ireland, the Disability

Discrimination Act give you the right to ask for them.

These laws also protect you from being treated unfairly by your employer because of your MS.

Read more about working when you have MS and the help that's available in our booklet 'Work and MS: an employee's guide'.

Whether you work or not, our 'Benefits and MS' booklet tells you about help you might qualify for. This includes welfare benefits and help with transport or fuel costs.



# MS and how you're feeling

There's no right or wrong way to react when you're diagnosed with MS.

You might:

- burst into tears or feel stunned into silence
- feel sorry for yourself and ask 'why me?'
- feel angry and want to lash out at people
- feel grief because you don't see yourself as a healthy, carefree person anymore
- go into denial about your diagnosis
- or perhaps it's a relief to hear you have MS – especially if you had unexplained symptoms for a long time. Maybe you worried you had a terminal illness like a brain tumour.

All of these reactions are perfectly normal.

You may find that your reaction varies from day to day, perhaps

changing from fear to anger to sadness, to relief. Many people compare their emotional reaction to a rollercoaster ride, with its many ups and downs.

If you're finding it difficult, there's support available, for example from your medical team, including your MS nurse if you have one. Or talk to someone on the MS Helpline on **0808 800 8000** (closed on bank holidays and weekends).

You can also connect with other people with MS through the forums on our website, or through your local MS Society group (see page 31).

You may also want to read our booklet, 'MS and your emotions'.

Find more about how MS can affect your emotions at **[mssociety.org.uk/emotions](https://www.mssociety.org.uk/emotions)**

# Telling people

At some point it's likely you'll want to tell people you have MS.

This can feel like a scary thing to do. But it can help you to feel less alone with your MS. It can help you get the support you need from those around you.

You may want to tell everyone about your diagnosis – especially if you've been unwell for some time. Or you may want to tell only the people closest to you or people who need to know.

You may find it helpful to plan what you're going to say. Lots of people don't know about MS, or have their own ideas about it.

They may think everyone with MS needs a wheelchair, for example. So you'll have to be prepared to answer their questions.

You may want to give them copies of our booklets 'What is MS?' and

'For family and friends – when someone close to you has MS'. They can read these in their own time. You could also point them towards our website.

Before you tell people, be aware that they might not react like you'd expect, no matter how well you know them.

They could be more upset than you expected, or be surprisingly calm about it. You're the one with MS, but your diagnosis will affect their lives, too.

You can find more on telling people you have MS at [mssociety.org.uk/telling-people-you-have-ms](https://mssociety.org.uk/telling-people-you-have-ms)

## Do I have to tell my employer?

Most people don't have to tell their employer that they have MS. But you must if you're in the armed forces, or if your MS might affect health and safety at work.

You must also say something if you drive for your job. This includes if you drive vehicles (such as a taxi or HGV) that you need a special licence for.

You also have to mention your MS if it's led to restrictions being put on your driving licence, or if you're covered by your employer's insurance when you drive.

Even if you don't need to tell your employer, you may still want to tell them, so that they can give you any support you need at work.

There's more about work in our booklet 'Work and MS'. We also have a booklet for employers called 'MS in the workplace: an employer's guide'. This includes basic information about MS and outlines what they can do to support you, as well as what the law says they have to do.

As well as these guides, there's more information and our work toolkit on our website at [mssociety.org.uk/work](https://mssociety.org.uk/work)

### **Is there anyone I must tell?**

Yes, there are a few people you must tell.

If you drive, you have to tell the DVLA (DVA in Northern Ireland) about your diagnosis. You'll also have to declare your MS when you're buying certain types of insurance. You should also check all of your existing policies, to make sure you're still covered. Read more about driving and insurance in our booklets 'Motoring with MS' and 'Insurance and MS'.

**“Once I had a diagnosis I told everyone at work, and I never found it difficult to talk to colleagues about my MS. They were very sympathetic. I worked from home for two months, and am slowly building up my hours.”**

**Jane**

# Treatments for MS

There are over a dozen disease modifying therapies (DMTs) to treat relapsing MS.

## What are DMTs?

If your type of MS causes **relapses**, then DMTs are treatments that could control it or slow it down. They aren't a cure, but having one could make a real difference.

Having a DMT means you're less likely to get relapses, or your relapses will be less serious. A DMT can also reduce **inflammation** and prevent MS from damaging nerves. This means you should get less disability in the long run.

But no DMT will help if your MS doesn't cause relapses or inflammation in your brain.

You may have heard about a DMT that's not a drug. It's a stem cell therapy called HSCT (haematopoietic stem cell transplantation). You take chemotherapy drugs that destroy your **immune system**. Then some

of your stem cells are put back into your body. There, hopefully, they'll grow into a new immune system free of MS.

Only a few people get HSCT on the NHS. These are people whose MS can't be controlled by other DMTs.

## The benefits of starting treatment early

DMTs work better the earlier you start taking them. Damage caused by MS builds up over time. So the earlier you begin treatment, the more damage you can prevent.

## How early is early treatment?

Doctors recommend treatment starts as soon as possible after you're diagnosed. Within six weeks of being diagnosed you should have a follow-up appointment to talk about treatments.

Guidelines say that, whether you're on treatment or not, you should have a yearly review. MRI scans check how active your MS is and whether treatment is working. Ideally a scan at least every year is best, but it's up to your neurologist.

You and your neurologist will make decisions about your treatment based on your MRI scans and what your neurologist finds when they examine you.

## Are there DMTs for progressive MS?

DMTs can't help if you have progressive MS but you get no relapses, or no inflammation can be seen on your MRI scans. Unfortunately most people with progressive MS are in this position.

A DMT could be an option if you still get relapses or inflammation. Some people with secondary progressive MS still get relapses. There's one DMT they can have.

Inflammation can be seen on the MRI scans of some people with primary progressive MS. A small number of people with primary progressive MS even get relapses.

There's a new DMT that might work for both these groups of people - ocrelizumab (Ocrevus). In 2018 it became the first DMT available around the world for primary progressive MS. It's used in the first few years when there's still inflammation or relapses.

In September 2018 **NICE** said that, because of its cost, ocrelizumab wouldn't be available on the NHS for primary progressive MS. We're campaigning to change this. At the time of writing (early 2019) the makers of the drug and NHS England were in discussions about how to make it available on the NHS. For updates on this, visit [mssociety.org.uk/about-ms/treatments-and-therapies/disease-modifying-therapies/ocrelizumab](https://mssociety.org.uk/about-ms/treatments-and-therapies/disease-modifying-therapies/ocrelizumab)

Researchers are looking at other DMTs to see if they can help people with progressive MS that has inflammation. HSCT might be another option for a small number of people with progressive MS and who still have inflammation.

Research is looking for drugs that can repair damaged **myelin** around nerves and grow new nerves to replace dead or damaged ones. Find more about the latest research at [mssociety.org.uk/research](https://mssociety.org.uk/research)

Find more about treatments, including HSCT, in our booklet 'Disease modifying therapies (DMTs) for MS' at [mssociety.org.uk/dmts](https://mssociety.org.uk/dmts)

# How can I manage my symptoms?

There's one way you might be able to reduce your symptoms or stop new ones happening. That's to take a DMT if you're offered one.

If you get relapses, a DMT can mean you get fewer of them and they're less serious. In the long run, you could have less disability.

But, whether you take a DMT or not, there are also treatments for individual MS symptoms. These don't always make the symptom go away, but they can make it easier to deal with.

## Managing symptoms

What you eat or drink, medication, complementary therapies, and exercise can help with a lot of symptoms.

But don't struggle alone with a new symptom or an old one that's getting worse. Tell your MS nurse neurologist so they can see if anything can be done.

Sometimes the first treatment you try may not work, or you might find the side effects too much to deal with.

If you do, tell whoever gave it you that it's not right for you. There'll often be another treatment you can try. You may need to try a few before you find the right one.

As well as drug treatments, there are other ways to manage your symptoms. These include things like physiotherapy for muscle stiffness, or Botox for bladder problems.

Depending on your symptoms, you might see:

- **occupational therapists**
- physiotherapists
- continence advisers (for bladder and bowel problems)
- psychologists
- speech and language therapists.

To see all the professionals that might look after you, check out our who's who page at [mssociety.org.uk/whos-who](https://mssociety.org.uk/whos-who)

Our website has information on how to manage each of the symptoms. You can also read detailed information on each symptom in our range of booklets. See what's available at [mssociety.org.uk/publications](https://mssociety.org.uk/publications)

## Managing relapses

You might be prescribed **steroids** if a **relapse** is especially painful, distressing or has a big impact on your daily life. Steroids speed up your recovery from a relapse by dampening down **inflammation** in your brain or spinal cord. They're taken as tablets or as an infusion (or 'drip').

You don't have to take steroids for every relapse. Because of possible side effects, your doctor might want to limit how many times you have steroids each year. If it's a mild relapse, or you decide the steroid side effects are too much, you can decide not to take them.

Whether you take them or not won't make any difference to how you are once the relapse is over. They don't protect you from any lasting effects of a relapse, just speed up how soon you get over it.

Once the relapse is over, you may need support ('rehabilitation') to recover from it. This can combine different things like physiotherapy, **occupational therapy**, advice about what you eat, or support at work or at home. Read more in our booklet 'Managing a relapse'.



# Who'll be looking after me?

You may have a number of different people looking after you. It's worth knowing who can do what, and where to get the help you need.

## You

You know more about your MS than anybody else. You understand how symptoms affect you, mentally and physically.

You're best placed to monitor changes in your condition and to avoid triggers that make symptoms worse.

Remember that having the right information about MS will mean you'll be in a position to make better decisions for yourself. The more you know, the more you can help the professionals to help you.

## Your GP

GPs aren't MS specialists. Many only see a few people with MS in their careers. Don't expect them to fully understand MS.

Your GP can help you deal with many of your symptoms, referring you on to more specialist help when you need it. They can also contact your neurologist or, if you have one, your MS nurse when necessary (for example, if you have a **relapse**).

## Your MS nurse

MS nurses are nurses with specialist training in MS. They're a great source of information and advice. They can be a link between hospital, community services and social services.

You should be referred to an MS nurse as soon as you're diagnosed. They're often the first point of contact for any concerns you have about your MS.

If you haven't already been offered an appointment with an MS nurse, you can ask your GP or neurologist for a referral. Sometimes MS nurses take self-referrals, which means you can

ring them directly and ask for an appointment.

Not everywhere has MS nurses. If there's none in your area, ask if you can be referred to a specialist neurological nurse or someone else with an understanding of MS who you can contact if you need to.

To find MS nurse services in your area, the MS Trust has a service finder on their website at [mstrust.org.uk/about-ms/ms-services-near-me](https://www.ms-trust.org.uk/about-ms/ms-services-near-me)

## Your neurologist

Neurologists are doctors who specialise in treating conditions that affect the brain, spinal cord and nerves. You saw a neurologist when you were diagnosed with MS. Only neurologists can make the diagnosis.

Your neurologist will be interested in how your MS is developing long term, rather than the day-to-day management of it. Most people with MS only see their neurologist once or twice a year. You can ask to see them more often if you need to.

A neurologist can:

- prescribe DMTs
- arrange for scans and any other tests to check how active your MS is
- talk over new symptoms with you and ways to manage them

## Your multi-disciplinary team

The multi-disciplinary team (or MDT for short) is the group of health care specialists that work together to help you manage your MS.

As well as your neurologist and MS nurse, your multi-disciplinary team could have these people in it:

- a physiotherapist - for advice and treatment of difficulties you have moving around and other physical problems
- an occupational therapist - to help you deal with **fatigue** and provide practical solutions for problems affecting your life at work and home
- a social worker - for information and help with things like applying for benefits and housing



- a counsellor - to help you and people close to you to deal with the impact of MS on your life and relationships

Your GP or MS nurse can refer you to any of these or to other experts, such as continence advisers, dietitians and pain specialists.

You might not want or need to see these people now, but they're there in case you do in the future.

There's more on our website about the professionals who may be included in your team at [mssociety.org.uk/whos-who](https://mssociety.org.uk/whos-who)

### **What can I do to look after myself?**

The treatments you get from your health care team are only part of managing MS. There's a lot you can do to help look after yourself.

## Finding the right information

Having the right information about MS can mean you'll be more able to make better decisions for yourself.

There's so much information around, especially on the internet. It can be hard to know where to start.

It's important that the information you read is accurate, unbiased and up to date, so you can use it to make the right choices.

Be wary of anything that claims to be a miracle cure. Many companies try to cash in on conditions like MS by trying to sell unproven supplements, therapies and equipment.

You can get reliable information on managing MS from your health care team, from us, NHS Choices and the MS charities listed on page 31.

## Don't smoke

On pages 13 and 14 you'll have read about how smoking makes MS worse. If you smoke, giving up can reverse a lot of the extra

risks that come with smoking. Not smoking is one of the main things you can do to give your brain a better chance in its fight with MS.

Although we don't know for sure, there's evidence that passive smoking is bad for MS too. That's an extra reason to go smoke-free at home.

Get inspired to quit at [nhs.uk/oneyou/for-your-body/quit-smoking/](https://www.nhs.uk/oneyou/for-your-body/quit-smoking/)

Find more about the evidence on how smoking makes MS worse at [mssociety.org.uk/smoking](https://www.mssociety.org.uk/smoking)

## Eat well

If you eat a healthy, balanced diet your overall health and quality of life could improve. This is even more important when your body has to cope with living with a long-term condition like MS.

A lot of claims are made about how special diets can control MS. But there's no strong evidence that any diet is effective at managing MS.

Our booklet ‘Diet and nutrition’ looks at everything to do with food and MS. It covers vitamin supplements, diets that claim to treat MS, and foods to help with specific MS symptoms. Find it and more at [mssociety.org.uk/diet](https://mssociety.org.uk/diet)

## Exercise

Regular exercise can help with MS symptoms such as **fatigue**, balance, muscle stiffness, and bladder or bowel problems. It can make you feel better mentally too.

Being active doesn't have to mean playing a sport. It's all about finding the right activities to suit you and what you can do. It includes things like gardening, yoga and swimming.

There's also information about exercise in our booklet ‘Moving more with MS’, which comes with a free exercise DVD. Check out some of the exercises at [mssociety.org.uk/staying-active](https://mssociety.org.uk/staying-active)

## Complementary therapies

Many people with MS use complementary therapies to help

with particular symptoms, or to feel better.

These therapies include acupuncture, yoga, meditation, massage, hyperbaric oxygen therapy, homeopathy and osteopathy – although that's not all of them.

There's not a lot of evidence for many complementary therapies in MS, and there can be risks involved. So check with a health care professional before trying a complementary therapy.

Read more in our ‘Complementary and alternative medicine’ booklet and at [mssociety.org.uk/about-ms/treatments-and-therapies/complementary-and-alternative-therapies](https://mssociety.org.uk/about-ms/treatments-and-therapies/complementary-and-alternative-therapies)

**“It's a matter of trial and error. I've just started a treatment that works for some people, so I'm giving it a try.”**

**Chris**

# Where can I get support?

Feel you need extra support?  
Want to talk to someone who  
understands what you're  
going through? Try these.

## MS Helpline

The MS Helpline offers confidential emotional support and information to anyone affected by MS. They also have details of our online support for recently diagnosed people and their friends and family.

Call them on **0808 800 8000** (closed weekends and bank holidays) or email them on **helpline@mssociety.org.uk**

You can also send them a private message by visiting our Facebook page **facebook.com/MSSociety**. Use the 'send message' tab under the main picture.

## MS Society groups

Around 300 MS Society groups offer support. Through your local group you can meet other people with MS in your area, find out about local services and get support to help you deal with

your MS. Find your nearest group: **mssociety.org.uk/near-me**

## MS Society forum

The message boards on our website let you connect with other people affected by MS. There's one just for people who are newly diagnosed or going through the process of being diagnosed: **mssociety.org.uk/forum**

## Other MS organisations

### Shift MS

An online community popular with younger people with MS. Users can share, support and interact with each other throughout the **shift.ms** website.

### MS National Therapy Centres

A network of UK centres offering a range of therapies including physiotherapy and counselling: **msntc.org.uk**

### MS Trust

A charity offering information for anyone affected by MS: **mstrust.org.uk**

# New words explained

**central nervous system** or **CNS** – this is your brain and spinal cord. Nerves carry messages between both of them. These messages control how parts of your body work

**fatigue** – an overwhelming physical or mental tiredness common in people with MS. It can affect things like your arms, legs, concentration, memory, balance and eyesight, and takes longer to get over than normal tiredness

**immune system** – how your body defends you against things that give you infections or diseases (like viruses and bacteria). In MS this system goes wrong and attacks your central nervous system

**inflammation** – when your immune system reacts to attack or damage, it sends more blood and immune cells to the damaged area, making it swollen. When MS causes inflammation in your brain

and spinal cord it starts to damage it, triggering MS symptoms

**lesions** (also called ‘plaques’) – areas of damage caused by MS in your brain or spinal cord. They slow down or stop messages travelling down nerves, affecting your control of parts of your body. Lesions can be seen on MRI scans

**MRI scans** – pictures of inside your brain or spinal cord made by ‘magnetic resonance imaging’. They show where MS is causing damage through inflammation and damage to the myelin around the nerves

**myelin** – a fatty covering around a nerve which protects it. When you have MS, myelin is attacked by mistake by your immune system. This interrupts messages that travel along your nerves and that control parts of your body, causing the symptoms of MS

**nerves** – bundles of fibres along which signals travel from your brain or spinal cord. These signals control how parts of your body work and also make sure your thinking and memory work correctly

**NICE (National Institute for Health and Care Excellence)** – NICE is part of the Department of Health but independent from it. NICE produces guidelines for England and Wales on which drugs should be available on the NHS, and how they should be used

**obese** – being very overweight. Defined by the NHS as a body mass index (BMI) of 30 and over. Find out your BMI at [www.nhs.uk/Tools/Pages/Healthyweightcalculator.aspx](http://www.nhs.uk/Tools/Pages/Healthyweightcalculator.aspx)

**occupational therapist** – someone who supports you to do daily tasks and keep your independence. They suggest practical changes to how you do things and alterations to where you work or live

**plaques** – see ‘lesions’

**relapse** – a flare up or attack of your MS when you get new symptoms or old ones get worse. Symptoms then go away, get less noticeable or they can become permanent

**steroids** – corticosteroids (not to be confused with anabolic steroids that body builders take). They dampen down inflammation in your brain or spinal cord during a relapse. They’re man-made versions of the hormones your body makes to deal with inflammation

# Further information

## Resources

Our award winning information resources cover every aspect of living with MS.

To order email:

**[shop@mssociety.org.uk](mailto:shop@mssociety.org.uk)** or visit  
**[mssociety.org.uk/publications](https://mssociety.org.uk/publications)**

## MS Helpline

The free MS Helpline offers confidential emotional support and information for anyone affected by MS, including family, friends and carers.

Information is available in over 150 languages through an interpreter service.

**0808 800 8000**

**(closed weekends and bank holidays)**

**[helpline@mssociety.org.uk](mailto:helpline@mssociety.org.uk)**

# About this resource

With thanks to all the people affected by MS and professionals who contributed to this booklet.

If you have any comments on this information, please send them to: [resources@mssociety.org.uk](mailto:resources@mssociety.org.uk)

**Disclaimer:** We have made every effort to ensure that the information in this publication is correct. We do not accept liability for any errors or omissions. Availability and prescribing criteria for drugs in various parts of the UK may change. Seek advice from the sources listed.

## References

A list of references is available on request. Call **0300 500 8084**.

## Photography

Photography: Paul Moane (cover), David Dunne (p6 and p18), Amit Lennon (p11 and p28) and Simon Rawles (p25).

This resource is also available in large print.

Call **0300 500 8084**  
or email [shop@mssociety.org.uk](mailto:shop@mssociety.org.uk)

# Contact us



## MS Helpline

Freephone 0808 800 8000

(closed on weekends and bank holidays)

[helpline@mssociety.org.uk](mailto:helpline@mssociety.org.uk)

## MS National Centre

0300 500 8084

[info@mssociety.org.uk](mailto:info@mssociety.org.uk)

[supportercare@mssociety.org.uk](mailto:supportercare@mssociety.org.uk)

## Online

[mssociety.org.uk](http://mssociety.org.uk)

[facebook.com/MSSociety](https://facebook.com/MSSociety)

[twitter.com/mssocietyuk](https://twitter.com/mssocietyuk)

## MS Society Scotland

0131 335 4050

[msscotland@mssociety.org.uk](mailto:msscotland@mssociety.org.uk)

## MS Society Northern Ireland

028 9080 2802

[nireception@mssociety.org.uk](mailto:nireception@mssociety.org.uk)

## MS Society Cymru

0300 500 8084

[mscymru@mssociety.org.uk](mailto:mscymru@mssociety.org.uk)

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